

Creating value that changes lives: online communities for the disabled or chronically unwell

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Abstract

People who suffer chronic illness or significant disability often find it difficult to participate in normal neighbourhood community life. Both the sufferer and their carers and family lose contact with neighbours, friends and the workplace and are unable to participate meaningfully. This study uses qualitative methods to examine online health communities for people suffering from two degenerative neurological diseases, Parkinson's Disease and Motor Neuron Disease and finds that participants in these online communities are creating peer-to-peer value through social capital exchange and a vibrant exchange of social support. The study finds that participation in online health communities can provide opportunities to significantly improve the lives of people who are disabled or chronically unwell.

Introduction

Consumers now use the internet as a valuable source of information in virtually all facets of their lives including health. A recent study found that 61% of American adults look online for health information (Fox & Jones, 2011), despite some concern amongst some medical practitioners about the reliability of information which can be published by anyone and can be variable in terms of its accuracy (Hardey, 2001). Social marketers and policy makers are interested in online communities built around medical conditions because the participants represent a subset of the population all affected by a specific health condition, identified as a market "fragment" by Bagozzi and Dholakia (2002). Other researchers argue that online communities are part of a cultural shift in the way consumers obtain and share information and support online (Barrette, 2006; Ewing, 2008). Barrette (2006) noted that 5 years ago there were some 25,000 online health communities to be found in Yahoo!, only one of many host sites for such communities.

Understanding the value of the online community to the participants is important to understanding how their behaviour can be influenced from within the community (Bagozzi & Utpal, 2002). An online health community can be considered a service to the participant, a form of self-service that delivers value such as information and social support. The communication flow between participants in online communities can influence participant purchasing and behaviour decisions (Brown et al., 2007; Chen & Xie, 2008; Kozinets, 2002) and provides an important channel for distribution of word-of-mouth information (Chen & Xie, 2008). It may also provide peer-to-peer value co-creation (Laing et al., 2011; Misra et al., 2008). Understanding behaviour within an online health community can provide insights into the value that participants receive, what brings participants back to the forum time after time, and then how the collective

behaviour of participants on the forum can influence individual behaviour and decision-making.

Traditionally clinicians or charitable support organisations have arranged “offline” (that is, face to face) support groups where patients and carers can meet others affected by the same illness (Lieberman & Williams, 1993 p 116-117) but these have required patients to attend meetings at pre-arranged times. With access to a computer and internet link a patient or carer can find other supportive online community members who are available at any time of the day, every day of the year, and the participants do not even have to leave home. (Braithwaite et al., 1999; Lindsay et al., 2009).

This paper focuses on two online health communities, both for people with degenerative and debilitating neurological diseases, Parkinson’s Disease and Motor Neuron Disease. Analysis of posts and threads recorded by participants are analysed for value delivered to participants in the form of social support and social capital within these two communities. Both Social Support and Social Capital are constructs within the field of Sociology that are linked to improved health outcomes (Beaudoin & Tao, 2007; Putnam, 2000). Prior research identifies evidence of social support within some online health communities, including one for Huntington’s Disease, another degenerative neurological disorder (Coulson et al., 2007). There is been little other literature relating to the value of online communities for people with degenerative neurological diseases, despite the potentially life-changing impact that participation in such communities can provide to those affected by these diseases. To date, no prior research has investigated stocks of social capital or the potential for peer-to-peer value co-creation within any online health communities associated with high levels of disability.

Parkinson’s Disease and Motor Neuron Disease are two incurable neurological diseases that have a deteriorating effect on mobility and thus affect the sufferer’s ability to participate in normal community life. Neither disease has a serious impact on cognitive function, so patients are mentally active, but physically impaired. Both patients and carers can be frustrated by the physical limitations imposed by these two diseases, and there is good reason to anticipate positive social benefits from participation in online health communities.

Method

Two online health communities were passively observed for a period of one month. The online communities were selected for this study based on their accessibility and level of activity. Neither required special access to read posts made to the community. The Motor Neuron Disease online community has more than 15,000 members and the Parkinson’s Disease community more than 2000.

The coding approach was guided by Kozinet’s (2002) method of “netnography” and the inferential approach to qualitative research described by Spiggle (1994). Each post has been scrutinised for evidence of social support, either solicited or provided. The social support framework used for this study is Cutrona and

Russell's (1990) social support typology which identifies five forms of social support: Emotional (feelings of comfort and security), Information (advice or guidance leading to possible solutions to a problem), Esteem (bolstering of self-confidence through positive feedback), Instrumental (concrete assistance) and Network Support (feeling of part of a group with common interests and concerns).

There is limited literature utilising qualitative methods to identify social capital within an online community, and no clear framework has emerged for identifying or measuring social support using qualitative methods. A particular challenge for this study is to identify what might constitute social capital within a community that is geographically disparate and characterised by high levels of physical disability. A social capital framework was developed specifically for this study to guide the identification of trust and generalised reciprocity, indicating social capital within the online communities.

Results

During the month of observation 661 posts were made to the MND Community by 133 participants and 137 posts were made to the PD Community by 35 participants. Females made 58% of the posts to the MND Community and 49% of posts to the PD community. Males made 32% of posts to the MND Community and 20% of posts to the PD Community. Remaining posts were made by posters of unknown gender.

Social Support was evident within both communities, as shown in Table 1. The value co-created by participants is evident in the differential patterns of support solicited and provided. Participants within both communities primarily solicit information support. In responding to the solicitations for information support, other participants provide additional, unsolicited emotional, esteem and network support.

Table 1: Social Support solicited and provided within the online communities

Social Support Category	PD Community		MND Community	
	Solicit	Provide	Solicit	Provide
Emotional Support	8 (20.5%)	36 (22.7%)	14 (12.3%)	85 (15.5%)
Esteem Support	2 (5%)	24 (15%)	1 (0.9%)	69 (12.6%)
Information Support	21 (54%)	47 (29.7%)	65 (57%)	214 (39.1%)
Instrumental Support	1 (2.5%)	1 (0.6%)	3 (2.6%)	2 (0.4%)
Network Support	7 (18%)	50 (32%)	31 (27.2%)	177 (32.4%)
Total Social Support Posts	39	158	114	547

Presence of social capital was identified within each community through demonstration of trust between community members, and also examples of generalised reciprocity. Posts were coded as indicating trust if the participants were exchanging personal details such as telephone and address details, or discussing intimate details about family or relationships. Generalised reciprocity was indicated by participants giving or contributing additional services to those requested, with no expectation of return. For example if a participant wrote a poem for the community or looked up information in a book to benefit the rest of the community this was considered to be generalised reciprocity and was coded as such.

Table 2 indicates that social capital, indicated by trust and generalised reciprocity, is present in both communities.

Table 2: Social Capital in the PD and MND online communities

	MND Community		PD Community	
	<u>Nbr</u>	<u>%</u>	<u>Nbr</u>	<u>%</u>
Reciprocity	65	82.3%	20	66.6%
Trust	23	17.7%	10	33.3%
Social Capital Total	88		30	
Social Capital % of Total Posts	58%		34.1%	

In addition to evidence of trust and generalised reciprocity evident within posts made to the two communities, it is apparent that group norms have been established between community members. These include a norm of using black humour to “laugh off” some of the more distasteful symptoms of the diseases, a refusal by participants to diagnose others based on self-reported symptoms and a norm of thanking those who respond to a post requesting information or other types of support.

Posts to both the PD and MND Communities have been reviewed for evidence of medical misinformation by one of Australia’s leading specialists in the field of neurology. No such evidence was found. Medical information shared between members of the PD and MND communities has been assessed as accurate and not in any way misleading. Contributions of medically accurate information are likely to contribute to the trust identified within the two communities as part of the social capital assessment.

Discussion and Conclusions

Both the MND and PD communities demonstrate high levels of social support provided to participants, especially information support, network support and emotional support. Examples of generalised reciprocity and trust, both components of social capital (Adler & Kwon, 2002; Stone, 2001), are identified in the PD and MND online communities.

The value to participation in these online health communities is in the support received that is additional to that solicited. The primary resource of the community is information embedded within individuals who are motivated to share it throughout the social network. Participants join the online communities to gain information and support, and in participation and posting they in turn provide value to the other community members in an ongoing cycle of peer-to-peer value co-creation (Ewing, 2008; Misra, et al., 2008).

In addition to an increased understanding of the value created by participants through their contributions within online health communities, this study has identified that participants are acting as social marketers, delivering healthcare messages and messages of support that reach a wide audience of community members. From a social marketing perspective this is more than word-of-mouth or “snowball” marketing. The participants are creating their own messages and norms (for example the refusal to diagnose) and these are then shared with other participants through social networks based on trust, as evidenced by the social capital presence within the community.

Conclusions

This study demonstrates that participants within online health communities are creating value at a peer-to-peer level. The communities studied are online social networks characterised by stocks of social capital that enable information and other support resources to flow between participants. Both social support and social capital have been linked with improved health outcomes and quality of life. Participation in an online health community cannot cure a degenerative neurological disease, but it can improve the quality of life for many participants. Practitioners involved in supporting people affected by these diseases typically establish face-to-face support group that, while helpful, are increasingly difficult to access as the disease progresses. This study has demonstrated that an alternative or supplementary approach could be to encourage people affected by these diseases to seek out online peer-to-peer support through online health communities. Such communities can provide not only the information support so often sought in the early days of illness, but also social and emotional support through involvement in a community of people who are going through a similar experience. Arguably of most significance an online health can provide an opportunity for significantly disabled people to give back to a community and assist in the generation of social capital and support for others.

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